

HELPING PATRONS UNRAVEL THE MYSTERY OF GENETIC INFORMATION

Carolyn Martin, MLS, AHIP
Consumer Health Coordinator
National Network of Libraries of Medicine
Pacific Northwest Region (NNLM PNR)
martinc4@uw.edu

Bobbi Newman, MLIS, MA
Community Engagement and Outreach Specialist
National Network of Libraries of Medicine
Greater Midwest Region (NNLM GMR)
bobbi-newman@uiowa.edu

**Genetics
Overview**

**Genomic
Health
Literacy**

**Genetic
Testing**

**Consumer
Health
Resources**

**Ethics &
Privacy**

***All of Us*
Research
Program**

NNL....Huh?

NIH

- **National Institutes of Health**
- Nation's research agency

NLM

- **National Library of Medicine**
- World's largest biomedical library

NNLM

- **National Network of Libraries of Medicine**
- Program of the NLM comprised of 8 Regional Libraries (RMLs) and 6 offices



The mission of NNLM is to advance the progress of medicine and improve the public health by:

- Providing all U.S. health professionals with equal access to biomedical information
- Improving the public's access to information to enable them to make informed decisions about their health

Genetics in the News

Human Gene Editing Receives Science Panel's Support

Scientists Say They Hope To Create A Human Genome In The Lab

Scientists Use Genetic Engineering To Vanquish Disease-Carrying Insects

Mail-Order CRISPR Kits Allow Absolutely Anyone to Hack DNA

Baltimore Ravens to hand out free DNA test kits

Clinical Genetics Has a Big Problem That's Affecting People's Lives

Unreliable research can lead families to make health decisions they might regret.

Genetic Testing for Athletic Ability

Can genes predict sporting talent?

Opioids: Can a Genetic Test Identify an Addict in the Making?

Genetically Modified Humans? How Genome Editing Works

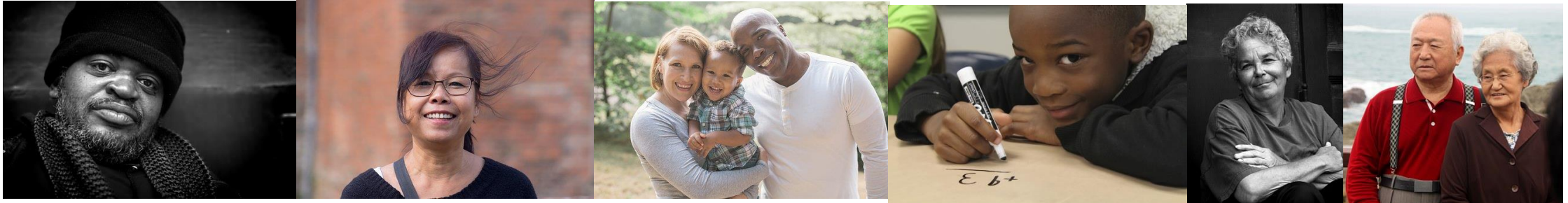
Birth of Baby With Three Parents' DNA Marks Success for Banned Technique

Genomic Health Literacy

Lack biology basics

Lack mathematical concepts

Low health literacy



Definitions

Genomic Health Literacy

- The capacity to obtain, process, understand, and use genomic information for health related decision making.

Genomic Science Literacy

- The knowledge of basic genetics and genomics concepts and processes needed to build conceptual understanding, and the necessary mathematical knowledge to support this comprehension.

Leading causes of death

1. Heart disease: 633,942
2. Cancer: 595,930
3. Chronic lower respiratory diseases: 155,041
4. Accidents (unintentional injuries): 146,571
5. Stroke (cerebrovascular diseases): 140,323
6. Alzheimer's disease: 110,561
7. Diabetes: 79,535
8. Influenza and pneumonia: 57,062
9. Nephritis, nephrotic syndrome, and nephrosis: 49,959
10. Intentional self-harm (suicide): 44,193

The Story of You



[The Story of You](#)

CATEGORIES OF DISEASES ATTRIBUTED TO GENES

- Chromosomal Diseases
- Monogenic Diseases
- Multifactorial Diseases

Genetic Testing

INCLUDING DIRECT-TO-CONSUMER

Types of Genetic Tests

Diagnostic

Predictive

Carrier

Prenatal

Newborn
Screening








Research

Pharmacogenetic

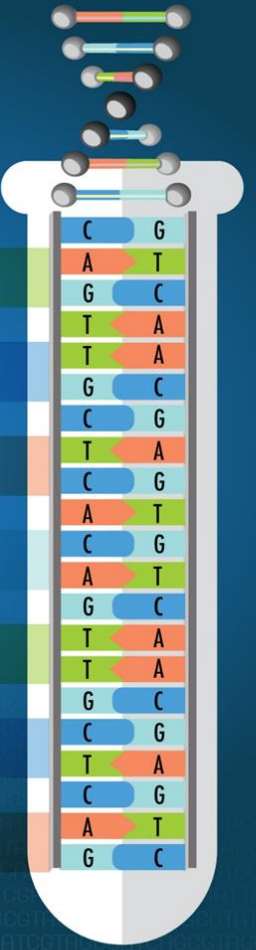
Clinical Uses of Genetic Tests

GENETIC TESTING
NHGRI FACT SHEETS
genome.gov

Genetic Tests Can Help to:

-  **Diagnose Your Disease**
-  **Pinpoint Genetic Factors That Caused Your Disease**
-  **Predict How Severe Your Disease Might Be**
-  **Choose the Best Medicine and Correct Dose**
-  **Discover Genetic Factors That Increase Your Disease Risk**
-  **Find Genetic Factors That Could Be Passed to Your Children**
-  **Screen Newborns for Certain Treatable Conditions**

Genetic Testing



Genetic Testing

Jean's Genetic Testing Timeline

Age 1 day: **newborn** testing for a few serious childhood diseases

Age 30: **carrier** testing (with her partner) before getting pregnant

Age 35: **predictive testing** when sister develops breast cancer at a young age

Age 45: **direct to consumer** genetic testing to investigate ancestry

Age 65: **pharmacogenomics** testing when Plavix wasn't effective



Genetic Testing Results

What genes and what variants did you test for?

- Different tests offered for the same conditions.
- Knowledge always changing.

Might not have enough examples in the database to determine associations between specific variants and specific conditions.

Might not have enough examples of people like you in the database.

Possibility of false positive and false negative results.

BRCA 1 & 2

- Majority of breast and ovarian cancers are not linked to BRCA
- Only 0.2% carry BRCA mutations
- U.S. Preventive Services Task Force recommends that women who have family members with breast, ovarian, tubal, or peritoneal cancer be assessed
- Women who are found to have a family history that may be associated with BRCA1 or BRCA2 mutations should receive genetic counseling and subsequent BRCA testing, if indicated
- Having the mutation does not necessarily mean cancer will develop, but it does increase risk

DTC BRCA test

U.S. Department of Health and Human Services

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FDA News Release

FDA authorizes, with special controls, direct-to-consumer test that reports three mutations in the BRCA breast cancer genes

Test only reports 3 out of more than 1,000 known BRCA mutations and negative result doesn't rule out increased cancer risk

SHARE TWEET LINKEDIN PIN IT EMAIL PRINT

For Immediate Release March 6, 2018

Release

[Español](#)

The U.S. Food and Drug Administration today authorized the Personal Genome Service Genetic Health Risk (GHR) Report for BRCA1/BRCA2 (Selected Variants). It is the first direct-to-consumer (DTC) test to report on three specific BRCA1/BRCA2 breast cancer gene mutations that are most common in people of Ashkenazi (Eastern European) Jewish descent. These three mutations, however, are not the most common BRCA1/BRCA2 mutations in the general population.

Inquiries

Media

Deborah Kotz
301-796-5349

Consumers

888-INFO-FDA

Related Information

- FDA allows marketing of first direct-to-consumer tests that provide genetic risk information
- Commissioner statement on consumer tests that evaluate genetic health risks
- Diagnostic tests

Follow FDA

[FDA announcement](#)

23andMeBlog

HOME CATEGORIES ALL POSTS

A Major Milestone in Consumer Health Empowerment


March 6, 2018 By AnneW under Health and Traits

We wear pink ribbons. We walk or run for the cause. We have a month for awareness, and yet many women who have a higher risk variant in the BRCA1 or BRCA2 genes remain unaware of their heightened genetic risk for breast and ovarian cancer until a doctor diagnoses them with cancer.^[1]

That's a failure.

This is not a radical indictment of the American healthcare system; it's just a fact. We are very good at treating illnesses, but not at preventing them.

Under the current system, there are specific guidelines for BRCA screening that limit who has access to BRCA testing. Family history of cancer and Ashkenazi Jewish ancestry are the most common criteria for screening guidelines. However we have seen at 23andMe that many people do not know their family medical history or their ancestry. So,



[23andMe announcement](#)

Genetic Testing- is it necessary?

Questions to ask:

- Am I in the group at risk and should I get tested?
- If I decide to get tested, what do the results mean?
- What are my treatment options based on results?
- How do I decide on treatment?



Making smart decisions about genetic testing:

Avoid unneeded tests, and understand the tests you need

Genetic testing can help identify an inherited condition or disease risk. The test results might help you and your doctor:

- Choose ways to prevent or treat a condition.
- Decide which screening tests you need (to find a disease at an early stage when it might be more treatable).

Genetic testing may also tell you which family members are at risk.

But sometimes a genetic test is not the best way to find an inherited condition or disease risk. A routine blood test or procedure might be just as good. And it might be less costly and more easily available.

Know what to expect.

Before you have any genetic test, you should understand its possible benefits, harms, and limitations. And you should think about how it might affect others in your family.

Talk to your doctor or a medical geneticist.

- Diagnose genetic conditions.
- Select the most appropriate genetic tests.
- Explain test results to patients and their families.
- Recommend personalized treatment and prevention options.



Choosing Wisely

Genetic Counselors

- Evaluate family history and medical records
- Assist in making decisions regarding genetic testing
- Identify and interpret risks of inherited disorders, increase the family's understanding of a genetic condition
- Discuss options regarding disease management and the risks and benefits of further testing and other options
- Help the individual and family identify the psychosocial tools required to cope with potential outcomes
- Reduce the family's anxiety

[National Society of Genetic Counselors](#)

Direct to Consumer Testing



SUPERHERO
DNA Test



NUTRITION
DNA Test




FITNESS
DNA Test


Genomic Testing- Athletic Ability

- Over 36 companies marketing genetic tests
- Poor quality control
- Targeted to coaches and parents
- Individuals also wanting to focus training


Achieve
your full potential.



Increase
your athletic performance.



Harness
your natural ability through
personalized genomics.


www.GenomicExpress.com

Genomic Testing- Consensus Statement

Consensus statement



OPEN ACCESS

Direct-to-consumer genetic testing for predicting sports performance and talent identification: Consensus statement

Nick Webborn,¹ Alun Williams,² Mike McNamee,³ Claude Bouchard,⁴ Yannis Pitsiladis,⁵ Ildus Ahmetov,⁶ Euan Ashley,⁷ Nuala Byrne,⁸ Silvia Camporesi,⁹ Malcolm Collins,¹⁰ Paul Dijkstra,¹¹ Nir Eynon,¹² Noriyuki Fuku,¹³ Fleur C Garton,¹⁴ Nils Hoppe,¹⁵ Søren Holm,¹⁶ Jane Kaye,¹⁷ Vassilis Klissouras,¹⁸ Alejandro Lucia,¹⁹ Kamiel Maase,²⁰ Colin Moran,²¹ Kathryn N North,¹⁴ Fabio Pigozzi,²² Guan Wang⁵

► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/bjsports-2015-095343>).

For numbered affiliations see end of article.

Correspondence to
Dr Alun Williams, MMU Sports Genomics Laboratory, Department of Exercise and Sport Science, Manchester Metropolitan University, Crewe Green Road, Crewe, CW1 5DU, UK
A.G.Williams@mmu.ac.uk

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ABSTRACT

The general consensus among sport and exercise genetics researchers is that genetic tests have no role to play in talent identification or the individualised prescription of training to maximise performance. Despite the lack of evidence, recent years have witnessed the rise of an emerging market of direct-to-consumer marketing (DTC) tests that claim to be able to identify children's athletic talents. Targeted consumers include mainly coaches and parents. There is concern among the scientific community that the current level of knowledge is being misrepresented for commercial purposes. There remains a lack of universally accepted guidelines and legislation for DTC testing in relation to all forms of genetic testing and not just for talent identification. There is concern over the lack of clarity of information over which specific genes or variants are being tested and the almost universal lack of appropriate genetic counselling for the interpretation of the genetic data to consumers. Furthermore independent studies have identified issues relating to quality control by DTC laboratories with different results being reported from

of the evidence in relation to genetic testing and the limitations of current knowledge. This article reviews the issues around the currently available evidence behind the genetic testing, comments on the ethical considerations and makes recommendations about such tests.

STATEMENT ON BACKGROUND TO THE CONSENSUS PROCESS

A group of world experts in the field of genomics, exercise, sport performance, disease, injury and antidoping gathered with the International Federation of Sports Medicine (FIMS) Scientific Commission for a symposium to discuss the current state of knowledge and to share ideas. One key concern was the misuse of research evidence and the misinformation about genetic testing, particularly when marketed directly to the public, coaches or parents. This is known as DTC testing for the purpose of talent identification and to assess potential for future sports performance. There have been


Concerns






- Privacy and legality
- Who has access?
- What all is being done now and in the future with the information?
- Unexpected surprises?
- Test results can vary among companies
- Validity of tests
- No counseling provided


Benefits

- Learn more about own health
- Learn more about ethnicity and family history
- Bring awareness to family health issues for future generations
- Motivation to work on health habits
- Encourages patient engagement
- Contributing to advancement of healthcare and science
- Moral obligation

Genetics Home Reference

 U.S. NATIONAL LIBRARY OF MEDICINE


 Your Guide to Understanding Genetic Conditions

[Health Conditions](#)
[Genes](#)
[Chromosomes & mtDNA](#)
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[Help Me Understand Genetics](#)

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[Help Me Understand Genetics](#)
[Genetic Testing](#)
[What is direct-to-consumer genetic testing?](#)

What is direct-to-consumer genetic testing?

Traditionally, genetic tests have been available only through healthcare providers such as physicians, nurse practitioners, and genetic counselors. Healthcare providers order the appropriate test from a laboratory, collect and send the samples, and interpret the test results. Direct-to-consumer genetic testing refers to genetic tests that are marketed directly to consumers via television, print advertisements, or the Internet. This form of testing, which is also known as at-home genetic testing, provides access to a person's genetic information without necessarily involving a doctor or insurance company in the process.

If a consumer chooses to purchase a genetic test directly, the test kit is mailed to the consumer instead of being ordered through a doctor's office. The test typically involves collecting a DNA sample at home, often by swabbing the inside of the cheek, and mailing the sample back to the laboratory. In some cases, the person must visit a health clinic to have blood drawn. Consumers are notified of their results by mail or over the telephone, or the results are posted online. In some cases, a genetic counselor or other healthcare provider is available to explain the results and answer questions. The price for this type of at-home genetic testing ranges from several hundred dollars to more than a thousand dollars.

For more information about direct-to-consumer genetic testing:

The American College of Medical Genetics, which is a national association of doctors specializing in genetics, has issued [a statement on direct-to-consumer genetic testing](#).

The American Society of Human Genetics, a professional membership organization for specialists in genetics, has also issued [a statement on direct-to-consumer genetic testing in the United States](#).

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Genetic Testing

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Research <ul style="list-style-type: none"> Statistics and Research Clinical Trials Journal Articles 	Resources <ul style="list-style-type: none"> Reference Desk Find an Expert 	For You <ul style="list-style-type: none"> Patient Handouts

Summary

Genetic tests are tests on blood and other tissue to find [genetic disorders](#). Over 2000 tests are available. Doctors use genetic tests for several reasons. These include

- Finding genetic diseases in unborn babies
- Finding out if people carry a gene for a disease and might pass it on to their children
- Screening embryos for disease
- Testing for genetic diseases in adults before they cause symptoms
- Making a diagnosis in a person who has disease symptoms
- Figuring out the type or dose of a medicine that is best for a certain person

People have many different reasons for being tested or not being tested. For some, it is important to know whether a disease can be prevented or treated if a test is positive. In some cases, there is no treatment. But test results might help a person make life decisions, such as family planning or insurance coverage. A [genetic counselor](#) can provide information about the pros and cons of testing.

NIH: National Human Genome Research Institute

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MEDICAL ENCYCLOPEDIA

BRCA1 and BRCA2 gene testing
Buccal smear
Genetic testing and your cancer risk

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CONSUMER INFORMATION

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Español

Vea esta página en español

Direct-to-Consumer Genetic Tests

Could a simple medical test tell you if you are likely to get a particular disease? Could it evaluate your health risks and even suggest a specific treatment? Could you take this test in the privacy of your home, without a doctor's prescription or guidance?

Some companies say genetic testing can do all this and more. They claim that direct-to-consumer (DTC) genetic testing can screen for diseases and provide a basis for choosing a particular diet, dietary supplement, lifestyle change, or medication. These companies primarily sell their tests online and through multi-level marketing networks.

The Federal Trade Commission (FTC) wants you to know the facts about the DTC marketing of genetic tests.

Related Items


Anatomy of a Cancer Treatment Scam

- Dietary Supplements
- Miracle Health Claims
- Cancer Treatment Scams

→ [Genes and Genetic Tests](#)

→ [Interpreting the Results](#)

→ [Company Claims](#)

→ [If You're Considering a DTC Genetic Test](#)

→ [For More Information](#)

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VIDEO & MEDIA

American College of Medical Genetics and Genomics

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ACMG STATEMENT | Genetics
in Medicine

Direct-to-consumer genetic testing: a revised position statement of the American College of Medical Genetics and Genomics

ACMG Board of Directors¹

Disclaimer: These recommendations are designed primarily as an educational resource for medical geneticists and other health-care providers to help them provide quality medical genetics services. Adherence to these recommendations does not necessarily assure a successful medical outcome. These recommendations should not be considered inclusive of all proper procedures and tests or exclusive of other procedures and tests that are reasonably directed to obtaining the same results. In determining the propriety of any specific procedure or test, geneticists and other

clinicians should apply their own professional judgment to the specific clinical circumstances presented by the individual patient or specimen. It may be prudent, however, to document in the patient's record the rationale for any significant deviation from the recommendations.

Genet Med advance online publication 17 December 2015

Key Words: consumer; direct-to-consumer; genetic testing; self-testing; OTC

With ongoing genetic discoveries and improvements in technology, more genetic tests are available than ever before. Along with greater availability has come increased consumer demand for genetic tests and expansion of direct-to-consumer testing. The American College of Medical Genetics and Genomics (ACMG) has revised its 2008 e-publication regarding this issue (ACMG Statement on Direct-to-Consumer Genetic Testing, retired; available by request to acmg@acmg.net) and believes that it is critical for the public to realize that genetic testing is only one part of a complex process that includes genetic risk

- A genetics expert such as a certified medical geneticist or genetic counselor should be available to help the consumer determine, for example, whether a genetic test should be performed and how to interpret test results in light of personal and family history. A board-certified genetic counselor can help facilitate this process by providing information about the test and helping to explain test results. A number of risks can be reduced if a board-certified genetics professional is involved in genetic testing, including inadequate or lack of informed consent.

ACMG

Questions to ask before using a Direct to Consumer Genetic Test

- Is the test right for me?
- What are the company claims?
- What do I hope to find out?
- Am I ready to hear something unexpected?
- Who will the results affect besides me?
- What happens to my genetic information?

Consumer Resources

PATIENT AND K-12 EDUCATION

MedlinePlus



- Section: Genetics/Birth Defects
- Health Topic pages:
 - Genetics
 - Genetic testing
 - Genetic counseling
 - Genetic disorders
 - Genetic brain disorders
 - Genes and gene therapy
- text word search

MedlinePlus

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Genetics/Birth Defects

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[Achondroplasia](#) [see Dwarfism](#)

[Adrenoleukodystrophy](#) [see Leukodystrophies](#)

[Alpha-1 Antitrypsin Deficiency](#)

[Amniocentesis](#) [see Prenatal Testing](#)

[Anencephaly](#) [see Neural Tube Defects](#)

[Arnold-Chiari Malformation](#) [see Chiari Malformation](#)

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[Brain Malformations](#)

[Canavan Disease](#) [see Leukodystrophies](#)

[Cephalic Disorders](#) [see Brain Malformations](#)

[Cerebral Palsy](#)

[Charcot-Marie-Tooth Disease](#)

[Chiari Malformation](#)

[Chorionic Villi Sampling](#) [see Prenatal Testing](#)

[Cleft Lip and Palate](#)

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MedlinePlus – stroke topic page

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Stroke

Also called: Brain attack, CVA

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Summary

A stroke is a medical emergency. Strokes happen when blood flow to your brain stops. Within minutes, brain cells begin to die. There are two kinds of stroke. The more common kind, called **ischemic stroke**, is caused by a **blood clot** that blocks or plugs a blood vessel in the brain. The other kind, called **hemorrhagic stroke**, is caused by a blood vessel that breaks and bleeds into the brain. "Mini-strokes" or **transient ischemic attacks (TIAs)**, occur when the blood supply to the brain is briefly interrupted.

Symptoms of stroke are

- Sudden numbness or weakness of the face, arm or leg (especially on one side of the body)
- Sudden confusion, trouble speaking or understanding speech
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- Sudden severe headache with no known cause

Get Stroke updates by email

MEDICAL ENCYCLOPEDIA

[BAER - brainstem auditory evoked response](#)

[Brain herniation](#)

[Brain surgery](#)

[Brain surgery - discharge](#)

[Craniotomy - slideshow](#)

[EEG](#)

Specifics

- [Hemorrhagic Stroke: MedlinePlus Health Topic](#) (National Library of Medicine)
Also in Spanish
- [Ischemic Stroke: MedlinePlus Health Topic](#) (National Library of Medicine)
Also in Spanish
- [Spinal Cord Infarction](#) (National Institute of Neurological Disorders and Stroke)
- [Wallenberg's Syndrome](#) (National Institute of Neurological Disorders and Stroke)

Genetics

- [Genetics Home Reference: cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy](#) (National Library of Medicine)
- [Genetics Home Reference: Grange syndrome](#) (National Library of Medicine)
- [Genetics Home Reference: mitochondrial encephalomyopathy, lactic acidosis, and stroke-like episodes](#) (National Library of Medicine)
- [Genetics Home Reference: moyamoya disease](#) (National Library of Medicine)

Images

- [Craniotomy - slideshow](#) (Medical Encyclopedia)
Also in Spanish

Health Check Tools

- [Test Your Stroke Knowledge](#) (National Institute of Neurological Disorders and Stroke)
- [What's Your Stroke I.Q.?](#) (American Heart Association)

Videos and Tutorials

- [Know Stroke: Know the Signs, Act in Time Video](#) (National Institute of Neurological Disorders and Stroke)

Statistics and Research

- [FastStats: Cerebrovascular Disease or Stroke](#) (National Center for Health Statistics)
- [Heart Disease and Stroke Statistics](#) (American Heart Association)
- [Preventing Stroke Deaths](#) (Centers for Disease Control and Prevention)
Also in Spanish

Clinical Trials

- [ClinicalTrials.gov: Carotid Stenosis](#) (National Institutes of Health)
- [ClinicalTrials.gov: Cerebrovascular Disorders](#) (National Institutes of Health)

MedlinePlus – text search



The screenshot shows the MedlinePlus website interface. At the top, the NIH logo and 'U.S. National Library of Medicine' are visible. The MedlinePlus logo with the tagline 'Trusted Health Information for You' is on the left. A search bar at the top right contains the text 'genetics' and a 'GO' button. Below the search bar, there are links for 'About MedlinePlus', 'Site Map', 'FAQs', and 'Customer Support'. The main navigation bar includes 'Health Topics', 'Drugs & Supplements', 'Videos & Tools', and a language selector for 'Español'. Below the navigation bar, the page shows 'Home → Search Results' and a 'Search Help' link. On the left side, there are sections for 'Related Topics' (Seizures, Epilepsy, Ovarian Cancer, Breast Cancer, Genetic Counseling) and 'Refine by Type' (All Results: 8,846; Health Topics: 390; External Health Links: 4,757; Drugs and Supplements: 36; Medical Encyclopedia: 418; MedlinePlus Magazine: 205; Multiple Languages; National Institutes of Health: 2,832). Below this is a 'Refine by Format' section (All Results: 8,846; PDF: 153; Images: 36; Videos: 19). The main content area features a 'Genetic Disorders' section with a blue header, a paragraph about genes, an image of chromosomes, and a paragraph about mutations. Below this, it says '(Read more)'. At the bottom of the main content area, it says 'Results 1 - 10 of 5,973 for genetics'. The search results list three items: 1. Genetic Disorders (National Library of Medicine), 2. Genetic Brain Disorders (National Library of Medicine), and 3. Genetic Counseling (National Library of Medicine). Each item has a brief description and a link to the full article.

Textword search 'genetics'

Genetics Home Reference

The screenshot shows the homepage of the Genetics Home Reference website. At the top is a blue header with the NIH logo and the text 'U.S. NATIONAL LIBRARY OF MEDICINE'. Below this is a navigation bar with the 'Genetics Home Reference' logo, the tagline 'Your Guide to Understanding Genetic Conditions', and a search bar. A secondary navigation bar contains links for 'Health Conditions', 'Genes', 'Chromosomes & mtDNA', 'Resources', and 'Help Me Understand Genetics'. The main content area features a large banner with the text 'Genetics Home Reference provides consumer-friendly information about the effects of genetic variation on human health.' Below the banner, there are three main sections: 'Health Conditions' with a description 'More than 1,100 health conditions, diseases, and syndromes' and a 'Browse A-Z' button; a 'New & Updated' section with a list of recent updates including 'Hartnup disease', 'multiple myeloma', and 'SYNGAP1-related intellectual disability'; and a 'Genes' section at the bottom left with a DNA helix icon.

- Health conditions
- Genes
- Chromosomes and DNA
- Resources
- Genetic handbook (Help Me Understand Genetics)

[Genetics Home Reference](#)

Genetics Home Reference



Your Guide to Understanding
Genetic Conditions

Search



Health Conditions

Genes

Chromosomes & mtDNA

Resources

Help Me Understand Genetics



Health Conditions

Explore the signs and symptoms, genetic cause, and inheritance pattern of various health conditions.

0-9 A B C D E F G H I J K L M N O P
Q R S T U V W X Y Z

A-[alpha](#)lipoprotein Neuropathy, see [Tangier disease](#)

A-T, see [Ataxia-telangiectasia](#)

AAA, see [Triple A syndrome](#)

AAA syndrome, see [Triple A syndrome](#)

AADC deficiency, see [Aromatic L-amino acid decarboxylase deficiency](#)

Aarskog syndrome, see [Aarskog-Scott syndrome](#)

[Aarskog-Scott syndrome](#)

AAS, see [Aarskog-Scott syndrome](#)

AASA dehydrogenase deficiency, see [Pyridoxine-dependent epilepsy](#)

Aase syndrome, see [Diamond-Blackfan anemia](#)

Aase-Smith syndrome II, see [Diamond-Blackfan anemia](#)

AAT, see [Alpha-1 antitrypsin deficiency](#)

AATD, see [Alpha-1 antitrypsin deficiency](#)

AB variant, see [GM2-gangliosidosis, AB variant](#)

ABCB11-related intrahepatic cholestasis, see [Progressive familial intrahepatic cholestasis](#)

Learn More about Health Conditions


What does it mean if a disorder seems to run in my family?

What are the different ways in which a genetic condition can be inherited?

What are complex or multifactorial disorders?

What does it mean to have a genetic predisposition to a disease?

Genetics Home Reference




Health Conditions
Genes
Chromosomes & mtDNA
Resources
Help Me Understand Genetics

breast cancer

Print All
Open All
Close All

▶ Description
▶ Frequency
▶ Genetic Changes
▶ Inheritance Pattern
▶ Diagnosis & Management
▶ Other Names for This Condition
▶ Additional Information & Resources
▶ Sources for This Page
▶ Images



Health Conditions
Genes
Chromosomes & mtDNA
Resources
Help Me Understand Genetics

breast cancer

Print All
Open All
Close All

▶ Description
▶ Frequency
▶ Genetic Changes
▼ Inheritance Pattern

Most cases of breast cancer are not caused by inherited genetic factors. These cancers are associated with somatic mutations in breast cells that are acquired during a person's lifetime, and they do not cluster in families.

In hereditary breast cancer, the way that cancer risk is inherited depends on the gene involved. For example, mutations in the [BRCA1](#) and [BRCA2](#) genes are inherited in an [autosomal dominant pattern](#), which means one copy of the altered gene in each cell is sufficient to increase a person's chance of developing cancer. Although breast cancer is more common in women than in men, the mutated gene can be inherited from either the mother or the father.

In the other syndromes discussed above, the gene mutations that increase cancer risk also have an autosomal dominant pattern of inheritance. It is important to note that people inherit an increased likelihood of developing cancer, not the disease itself. Not all people who inherit mutations in these genes will ultimately develop cancer.

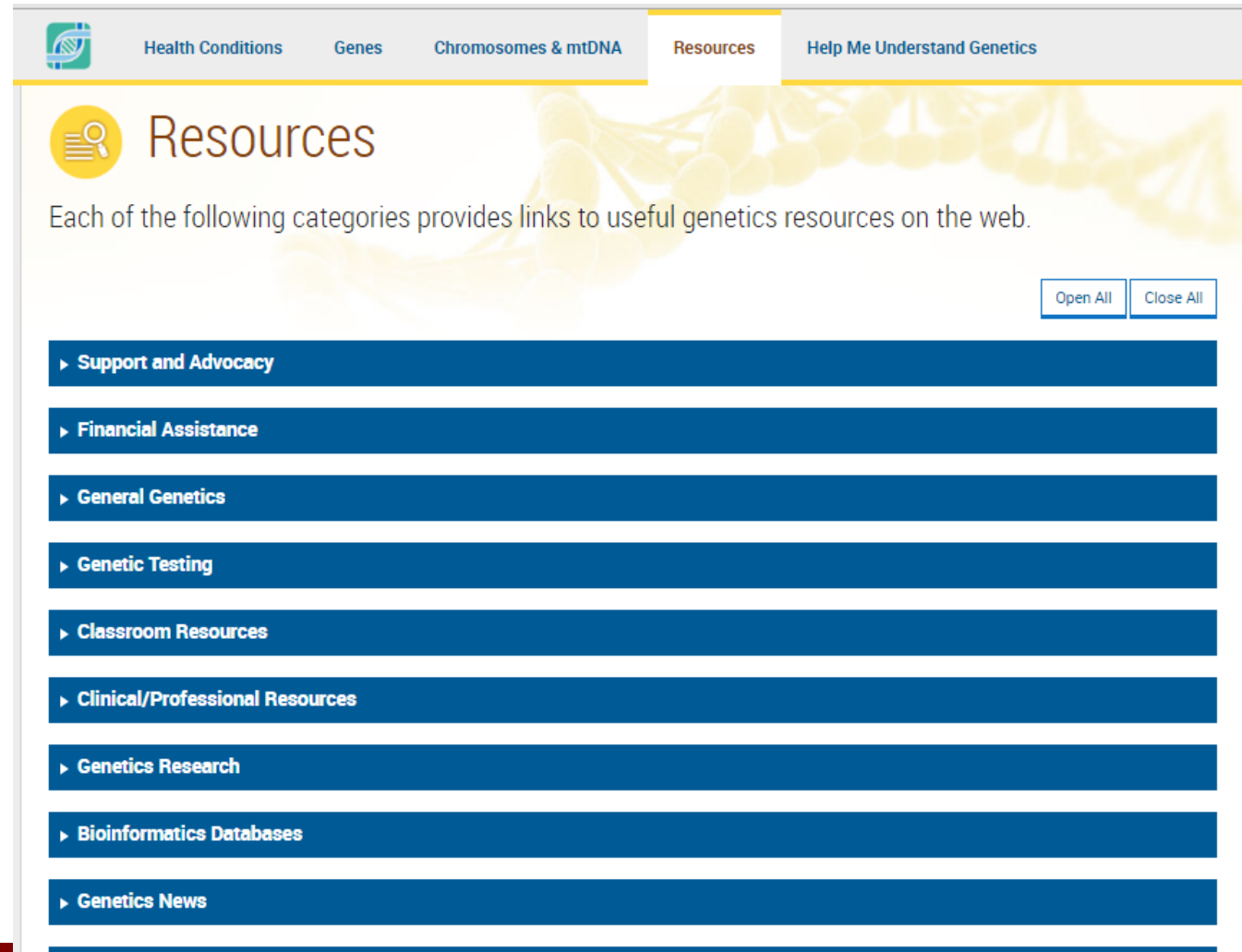
In many cases of breast cancer that clusters in families, the genetic basis for the disease and the mechanism of inheritance are unclear.

Related Information

[What does it mean if a disorder seems to run in my family?](#)
[What are the different ways in which a genetic condition can be inherited?](#)
[More about \[Inheriting Genetic Conditions\]\(#\)](#)


▶ Diagnosis & Management

Genetics Home Reference



The screenshot shows the 'Resources' section of the Genetics Home Reference website. At the top, a navigation bar includes links for 'Health Conditions', 'Genes', 'Chromosomes & mtDNA', 'Resources' (which is highlighted), and 'Help Me Understand Genetics'. Below the navigation bar, the 'Resources' section is titled with a magnifying glass icon and the word 'Resources'. A descriptive sentence states: 'Each of the following categories provides links to useful genetics resources on the web.' To the right of this text are two buttons: 'Open All' and 'Close All'. Below the text is a list of ten resource categories, each in a blue bar with a right-pointing arrow and the category name: 'Support and Advocacy', 'Financial Assistance', 'General Genetics', 'Genetic Testing', 'Classroom Resources', 'Clinical/Professional Resources', 'Genetics Research', 'Bioinformatics Databases', and 'Genetics News'.

Health Conditions Genes Chromosomes & mtDNA **Resources** Help Me Understand Genetics


 **Resources**


Each of the following categories provides links to useful genetics resources on the web.

[Open All](#) [Close All](#)

- ▶ **Support and Advocacy**
- ▶ **Financial Assistance**
- ▶ **General Genetics**
- ▶ **Genetic Testing**
- ▶ **Classroom Resources**
- ▶ **Clinical/Professional Resources**
- ▶ **Genetics Research**
- ▶ **Bioinformatics Databases**
- ▶ **Genetics News**

Genetics Home Reference

 [Health Conditions](#) [Genes](#) [Chromosomes & mtDNA](#) [Resources](#) [Help Me Understand Genetics](#)



Help Me Understand Genetics

Help Me Understand Genetics provides an introduction to fundamental topics related to human genetics, including illustrations and basic explanations of genetics concepts.

[Download Book \(6MB\)](#) [Open All](#) [Close All](#)

- ▶ [Cells and DNA](#)
- ▶ [Mutations and Health](#)
- ▶ [How Genes Work](#)
- ▶ [Gene Families](#)
- ▶ [Inheriting Genetic Conditions](#)
- ▶ [Genetics and Human Traits](#)
- ▶ [Genetic Consultation](#)
- ▶ [Genetic Testing](#)

NIH National Human Genome Research Institute- health information

National Human Genome Research Institute

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Highlights

The 2018 Jeffrey M. Trent Lecture in Cancer Research

NHGRI's Division of Intramural Research will present the 14th Jeffrey M. Trent Lecture in Cancer Research on March 15, 2018, 12:00 - 1:00 p.m., at the Lipsett Amphitheater, Building 10 (Clinical Center), on the National Institutes of Health Bethesda campus. Joan Brugge, Ph.D., co-director, Ludwig Center at Harvard Medical School, will deliver the lecture *Role of the TRPA1 Ca2+-permeable Channel in Oxidative Stress Defenses in Cancer*. Watch it at Genome TV Live on March 15 starting at 12:00 p.m. Eastern.

NIH researchers highlight virtual reality research on Reddit

Virtual Reality (VR) is a rapidly expanding area in tech and gaming. Now it's also playing an important role in medicine and health, expanding opportunities for researchers, clinicians and patients. Simulated experience can reduce stress, help doctors practice surgical techniques or allow medical students a way to practice their bedside manner in virtual scenarios. On February 23, NHGRI hosted a Reddit "Ask Me Anything" (AMA) with NIH researchers who use VR to study a host of research questions. Read our recap here.

NIH pilot project will match researchers to genes, gene variants of interest

The National Institutes of Health and Inova have launched a new match-making service between genes and gene variants and the researchers who study them. The Genomic Ascertainment Cohort (TGAC) project will be based in the Washington, D.C., area so that researchers can recall genotyped participants to examine the genes and gene variants that influence their phenotype.

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Genomics News

From the African Academy of Sciences: **African Academy of Sciences awards grants to better understand the diseases that affect Africa most**
March 1, 2018

From The National Institute of Environmental and Health Sciences: **Building Capacity in Africa for Genomics and Environmental Health Research**
February 20, 2018

From The Ohio State University Comprehensive Cancer Center: **New Report Labs Differ Widely in BRCA Testing Protocols**
February 16, 2018

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Quick Links

Director Eric Green

Strategic Planning

National Human Genome Research Institute

Search Genome.gov

Español

Research Funding
Research at NHGRI
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Health

Information about genetics and genomics, rare diseases, patient care and more

For Patients and the Public

Detailed information about genetic disorders, background on genetic and genomic science, pharmacogenomics, family health history tool and online health resources

- Community Engagement and Community Health
- Family History
- Genetics & Genomics Science & Research
- Genetic & Rare Diseases Information Center
- Genomic Medicine and Health Care
- Online Health and Support Resources
- Specific Genetic Disorders

For Health Professionals

Genetics and genomics information related to patient management, education, NIH and NHGRI research and ethical, legal and social issues

- Competency & Curricular Resources
- Genetics 101
- Genomic Medicine and Health Care
- Inter-Society Coordinating Committee (ISCC)
- New Horizons and Research
- Patient Management
- Policy and Ethics Issues

Highlights

Researchers pinpoint origin of sickle cell mutation

NHGRI researchers used whole genome sequence data to pinpoint the single origin of the sickle cell mutation to the "wet" period of the Sahara 7,300 years ago. The mutation causes blood hemoglobin to be crescent shaped, reducing its ability to carry oxygen. Charles N. Rotimi, Ph.D., study co-author and NHGRI senior investigator, said the finding overturns previous theories that the mutation arose in multiple locations. This will help clinicians redefine sickle cell subgroups and treat patients more effectively, said lead author Daniel Shriner, Ph.D. Read more in the March 8 *American Journal of Human Genetics*.

Reddit "Ask Me Anything" Recap: The importance of knowing your family health history

See Also

- GenomeTV
- Genomic Healthcare Branch
- Fact Sheets
- Genetic Education Resources for Teachers
- All About the Human Genome Project
- Health Archive
- On Other Sites:
- NHGRI's YouTube channel: GenomeTV

NHGRI

National Organization for Rare Disorders

ABOUT NEWS EVENTS CONTACT **DONATE**

 **NORD**
National Organization for Rare Disorders



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**7,000 RARE DISEASES
AFFECT 30 MILLION AMERICANS.
HOW CAN YOU HELP? #DOYOURSHARE**

DoYourShare.com

What's happening at NORD

 **RARE DISEASE DAY®**

 **NORD 35th ANNIVERSARY**
presenting the
RARE IMPACT AWARDS™
May 17, 2018 • Washington, D.C.
Registration Open!

 **Rare Summit**

 **Running for RARE**
Accepting Applications

Tools and Resources News

Education Resources

National Human Genome Research Institute

Search Genome.gov

Español

Research Funding
Research at NHGRI
Health
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Education

Educational materials about genetics and genomics

Smithsonian NHGRI Genome Exhibition
A genomics exhibition from the Smithsonian and NHGRI

About The Human Genome Project
Information on the history, progress and impact of the HGP

Talking Glossary of Genetic Terms
Terms and definitions used in genetic research with multimedia

Genomic Careers
Information on careers in genomics and genetics

National DNA Day
A unique day when everyone can learn more about genomics and genetics

Genetic Education Resources for Teachers
Teaching plans to present the science of genetics and genomics

Online Genetic Education Resources
A list of online resources for learning about genomics and genetics

Fact Sheets
Clearly written information on the institute, genetic research and genetic concepts

Online Education Kit
A web-based resource outlining the major history and developments of genomics

Highlights

The 2018 National DNA Day Essay Contest is open!

Geared to students grade 9-12 worldwide, the American Society of Human Genetics (ASHG) DNA Day Essay Contest celebrates National DNA Day by asking students to examine, question and reflect on important concepts in genetics. This year's question asks students if medical professionals should be required for all genetic testing, or should consumers have direct access to predictive genetic testing? **Deadline:** March 9, 2018, at 5:00 p.m. U.S. Eastern Time.

Genome Unlocking Life's Code goes international!

Genome: Unlocking Life's Code, the traveling genomics science exhibit created by NHGRI and the Smithsonian National Museum of Natural History, needs a passport ... because it's going international for the first time! The exhibit will move on to Science North in Sudbury, Ontario, from February 28 to April 1, 2018.

See Also

Education and Community Involvement Branch

GenomeTV

Genome Advance of the Month

Education Archive

On Other Sites:

Genome: Unlocking Life's Code
NHGRI Smithsonian Exhibition

GenomeTV
NHGRI's YouTube Channel

Health Conditions
Genes
Chromosomes & mtDNA
Resources
Help Me Understand Genetics

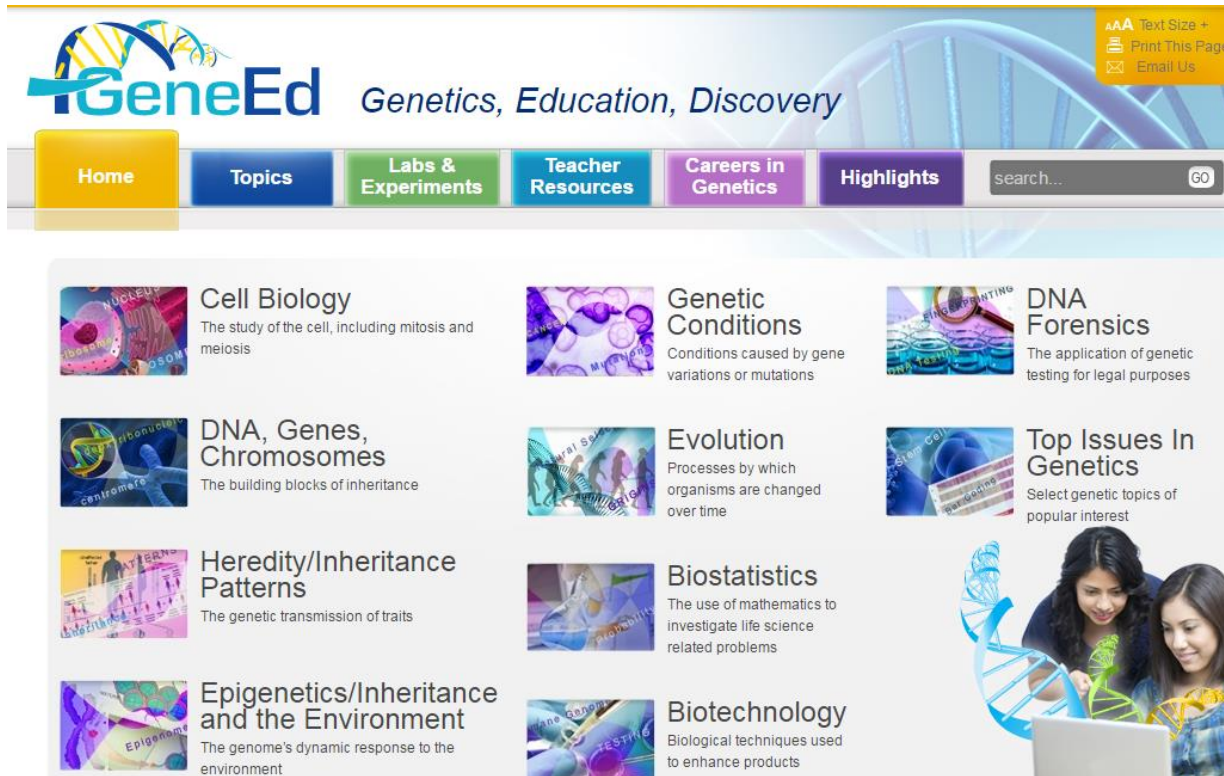
Help Me Understand Genetics

Help Me Understand Genetics provides an introduction to fundamental topics related to human genetics, including illustrations and basic explanations of genetics concepts.

Download Book (6MB)
Open All
Close All

- Cells and DNA
- Mutations and Health
- How Genes Work
- Gene Families
- Inheriting Genetic Conditions
- Genetics and Human Traits
- Genetic Consultation
- Genetic Testing

K-12 Resources



The GeneEd website features a blue and yellow DNA helix logo. The header includes navigation tabs: Home, Topics, Labs & Experiments, Teacher Resources, Careers in Genetics, and Highlights. A search bar is located on the right. The main content area displays eight topics with corresponding images and descriptions:

- Cell Biology**: The study of the cell, including mitosis and meiosis.
- Genetic Conditions**: Conditions caused by gene variations or mutations.
- DNA Forensics**: The application of genetic testing for legal purposes.
- DNA, Genes, Chromosomes**: The building blocks of inheritance.
- Evolution**: Processes by which organisms are changed over time.
- Top Issues In Genetics**: Select genetic topics of popular interest.
- Heredity/Inheritance Patterns**: The genetic transmission of traits.
- Biostatistics**: The use of mathematics to investigate life science related problems.
- Epigenetics/Inheritance and the Environment**: The genome's dynamic response to the environment.
- Biotechnology**: Biological techniques used to enhance products.

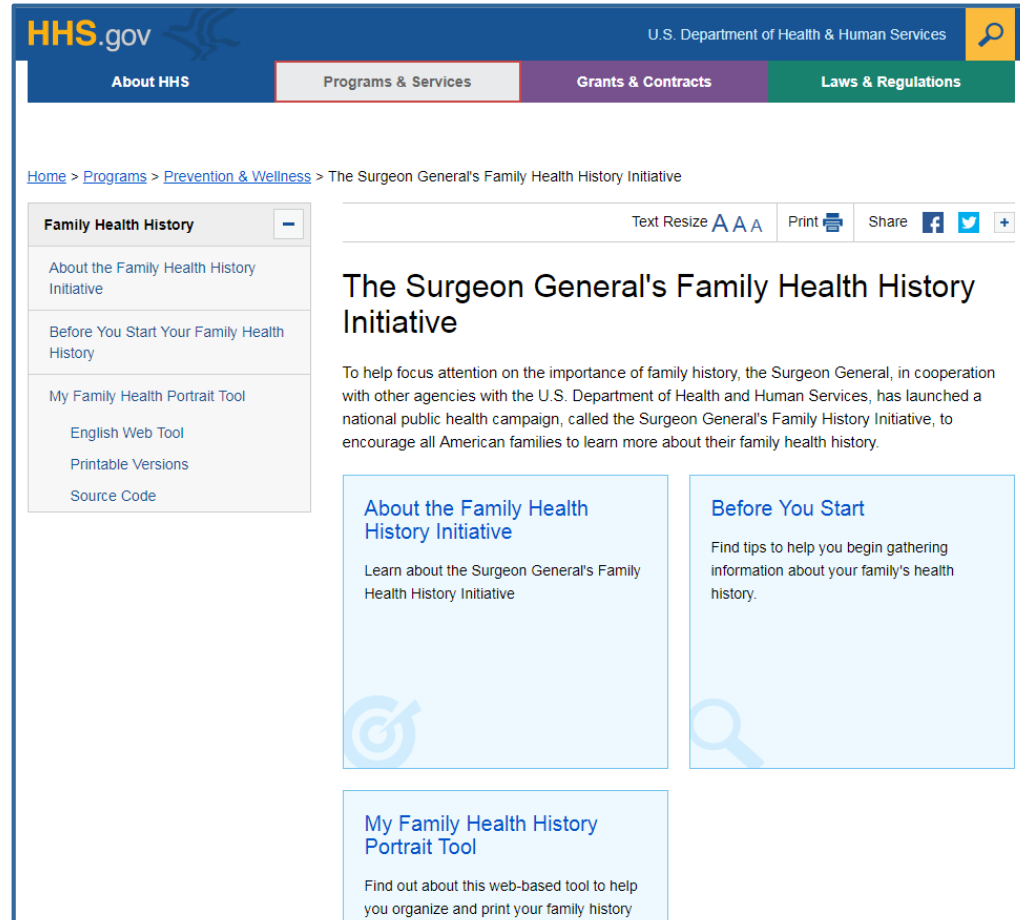
GeneEd



The Harry Potter's World website features a dark blue header with the NIH logo and navigation links: Databases, Find, Read, Learn, Explore NLM, Research at NLM, and NLM for You. The main content area displays the title "HARRY POTTER'S WORLD" and the subtitle "RENAISSANCE SCIENCE, MAGIC, AND MEDICINE". A large owl illustration is featured on the right. The text on the left reads: "In 1997, British author J. K. Rowling introduced the world to Harry Potter and a literary phenomenon was born. Although a fantasy story, the Harry Potter book series features magic that is based partially on Renaissance...". Below the text are three sections: "LEARN more" (with a "FIND OUT" button), "SEE the digital gallery", and "BOOK the traveling exhibition".

Harry Potter's World

My Family Health Portrait U.S. Surgeon General



The screenshot shows the HHS.gov website with a blue header. The header includes the HHS.gov logo, the text "U.S. Department of Health & Human Services", and a search icon. Below the header is a navigation bar with four tabs: "About HHS", "Programs & Services" (highlighted), "Grants & Contracts", and "Laws & Regulations".

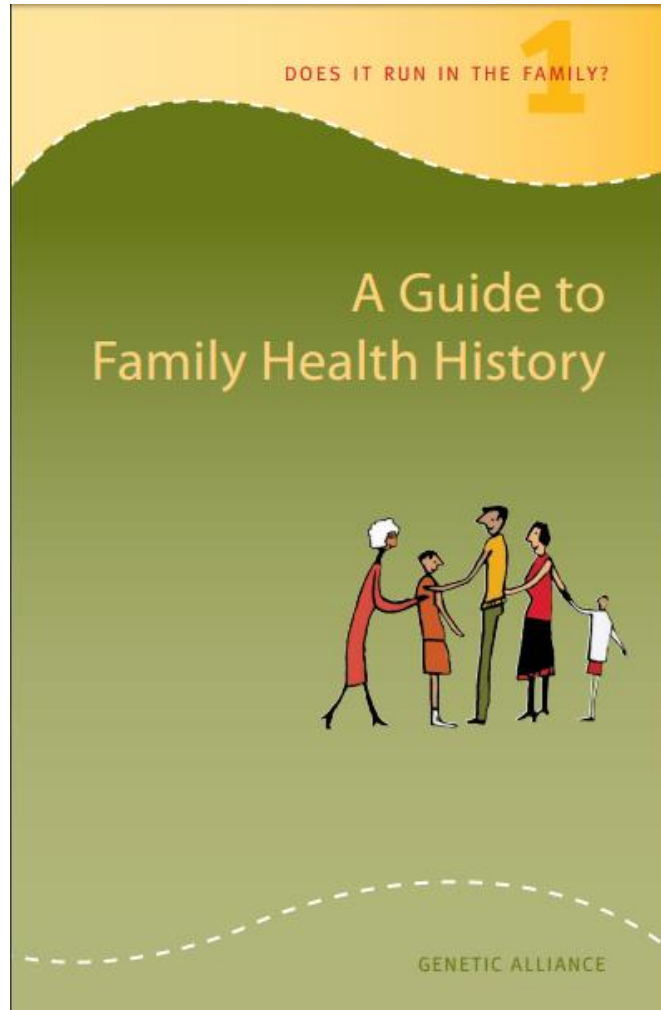
The main content area has a breadcrumb trail: [Home](#) > [Programs](#) > [Prevention & Wellness](#) > The Surgeon General's Family Health History Initiative. Below the breadcrumb trail is a sidebar on the left titled "Family Health History" with a minus sign icon. The sidebar contains four links: "About the Family Health History Initiative", "Before You Start Your Family Health History", "My Family Health Portrait Tool", and "English Web Tool".

The main content area features a title "The Surgeon General's Family Health History Initiative" and a paragraph: "To help focus attention on the importance of family history, the Surgeon General, in cooperation with other agencies with the U.S. Department of Health and Human Services, has launched a national public health campaign, called the Surgeon General's Family History Initiative, to encourage all American families to learn more about their family health history." Below the paragraph are three boxes: "About the Family Health History Initiative" (with a target icon), "Before You Start" (with a magnifying glass icon), and "My Family Health Portrait Tool" (with a target icon).

At the top right of the main content area, there are links for "Text Resize" (with "A A A" options), "Print" (with a printer icon), "Share" (with Facebook and Twitter icons), and a plus icon for more options.

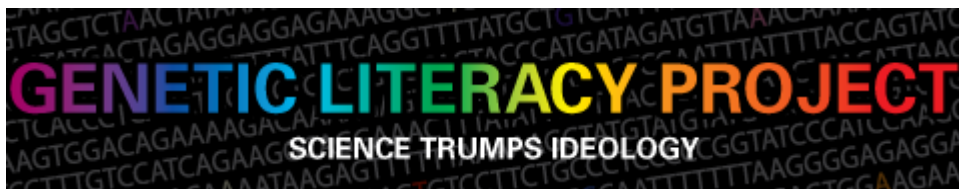
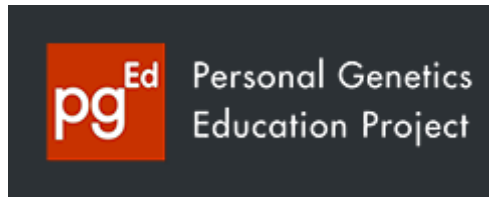
[Surgeon General's Family Health History Initiative](#)

Does It Run In the Family? Toolkit



[Does it Run In the Family? toolkit](#)

Literacy/Education Resources



Ethics and Privacy

Societal Concerns

- Who should have access to personal genetic information, and how will it be used?
- Who owns and controls genetic information?
- How does personal genetic information affect an individual and society's perceptions of that individual?
- How will genetic tests be evaluated and regulated for accuracy, reliability and utility?
- Where is the line between medical treatment and enhancement?
- Should testing be performed when no treatment is available?

GINA

GINA

GENETIC INFORMATION
NONDISCRIMINATION ACT

About | Contact

Genetic Information

What is genetic information and why is it important?

GINA & Health Insurance

What are GINA's health insurance protections?

GINA & Employment

What are GINA's employment protections?

What is GINA?

The Genetic Information Nondiscrimination Act of 2008 (GINA) is a federal law that protects individuals from genetic discrimination in health insurance and employment. Genetic discrimination is the misuse of genetic information. This resource provides an introduction to GINA and its protections in health insurance and employment. It includes answers to common questions and examples to help you learn. Choose from one of the boxes to the left to begin!

✉ Have questions, comments or suggestions? [Send us a note.](#)

🖨 [Click here](#) for a printer friendly version.

✉ For healthcare provider resources [click here.](#)

🖨 [Click here](#) for the GINA & You Information Sheet

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[GINA Help](#)

H. R. 1313

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All Legislation Examples: hr5, sres9, "health care"

Home > Legislation > 115th Congress > H.R.1313

H.R.1313 - Preserving Employee Wellness Programs Act
115th Congress (2017-2018) | [Get alerts](#)

BILL Hide Overview

Sponsor: [Rep. Foxx, Virginia \[R-NC-5\]](#) (Introduced 03/02/2017)

Committees: House - Education and the Workforce; Energy and Commerce; Ways and Means

Committee Reports: [H. Rept. 115-459](#)

Latest Action: House - 12/11/2017 Placed on the Union Calendar, Calendar No. 341. ([All Actions](#))

Tracker:

Introduced Passed House Passed Senate To President Became Law

More on This Bill
[Constitutional Authority Statement](#)
[CBO Cost Estimates \[1\]](#)

Subject — Policy Area:
Health
[View subjects >](#)

Summary (1) Text (2) Actions (13) Titles (3) Amendments (0) Cosponsors (5) Committees (3) Related Bills (0)

Summary: H.R.1313 — 115th Congress (2017-2018) [All Information](#) (Except Text)

[Listen to this page](#)

There is one summary for H.R.1313. [Bill summaries](#) are authored by [CRS](#).

Shown Here:
Introduced in House (03/02/2017)

Preserving Employee Wellness Programs Act

This bill exempts workplace wellness programs from: (1) limitations under the Americans with Disabilities Act of 1990 on medical examinations and inquiries of employees, (2) the prohibition on collecting genetic information in connection with issuing health insurance, and (3) limitations under the Genetic Information Nondiscrimination Act of 2008 on collecting the genetic information of employees or family members of employees. This exemption applies to workplace wellness programs that comply with limits on rewards for employees participating in the program.

Workplace wellness programs may provide for more favorable treatment of individuals with adverse health factors, such as a disability.

Collection of information about a disease or disorder of a family member as part of a workplace wellness program is not an unlawful acquisition of genetic information about another family member.



The NEW ENGLAND JOURNAL of MEDICINE

Perspective
JULY 6, 2017

Undermining Genetic Privacy? Employee Wellness Programs and the Law


Kathy L. Hudson, Ph.D., and Karen Pollitz, M.P.P.

Genetic information is becoming ubiquitous in research and medicine. The cost of genetic analysis continues to fall, and its medical and personal value continues to grow.

The Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits both employment and health insurance discrimination based on genetic information, and

PMID: 28537794

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Issues in Genetics


Policy, legal and ethical issues in genetic research




Coverage and Reimbursement of Genetic Tests
Information about insurance coverage for genetic testing




Human Subjects Research
Human subject participation for biomedical, clinical and social-behavioral research




Genetic Discrimination
How Americans are protected from discrimination based on their genetics




Regulation of Genetic Tests
How the federal government regulates genetic tests.




Privacy in Genomics
How best to ensure that genomic information remains private




Informed Consent
The rights of participants when consenting to research projects



Intellectual Property and Genomics
Can a gene be patented?




Genomics and Health Disparities
Ensuring that all populations benefit from the advances of genomics research



Genome Statute and Legislation Database
A database of state statutes and bills from 2007-2017 U.S. state legislative sessions


Highlights

Improving science policy and healthcare through the NHGRI-ASHG fellowship



The health and medical care of Americans is greatly influenced by the policy decisions that guide genomic research. NHGRI and the American Society for Human Genetics (ASHG) are committed to strengthening the workforce of policy makers and analysts with genetics professionals through their Genetics and Public Policy Fellowship. The 2017-2018 fellow, Nikki Meadows, Ph.D., has just finished her first rotation at NHGRI. Learn about her experiences and what motivates her to pursue a career in science policy.

New policy to protect research participants of NIH-funded research



The 21st Century Cures Act, enacted December 13, 2016, strengthened privacy protections for research participants. Now, a new policy specifically requires additional protections for sensitive information collected from participants as part of federally-funded research. The National Institutes of Health (NIH) recently put forth this new policy requiring all NIH-funded

See Also

- Policy and Program Analysis Branch
Staff Contact Information
- [Ethical, Legal and Social Implications Research Program](#)
NHGRI's Extramural Research Program
- GenomeTV
NHGRI's YouTube Channel
- Issues in Genetics Archive
Past Web content from the Issues in Genetics Portal
- Social and Behavioral Research Branch
NHGRI Intramural Research Program
- Online Bioethics Resources
Links to bioethics resources from around the Web

Informing the Public



CENTER FOR
GENETICS AND
SOCIETY



All of Us

1 MILLION + VOLUNTEERS

Precision Medicine



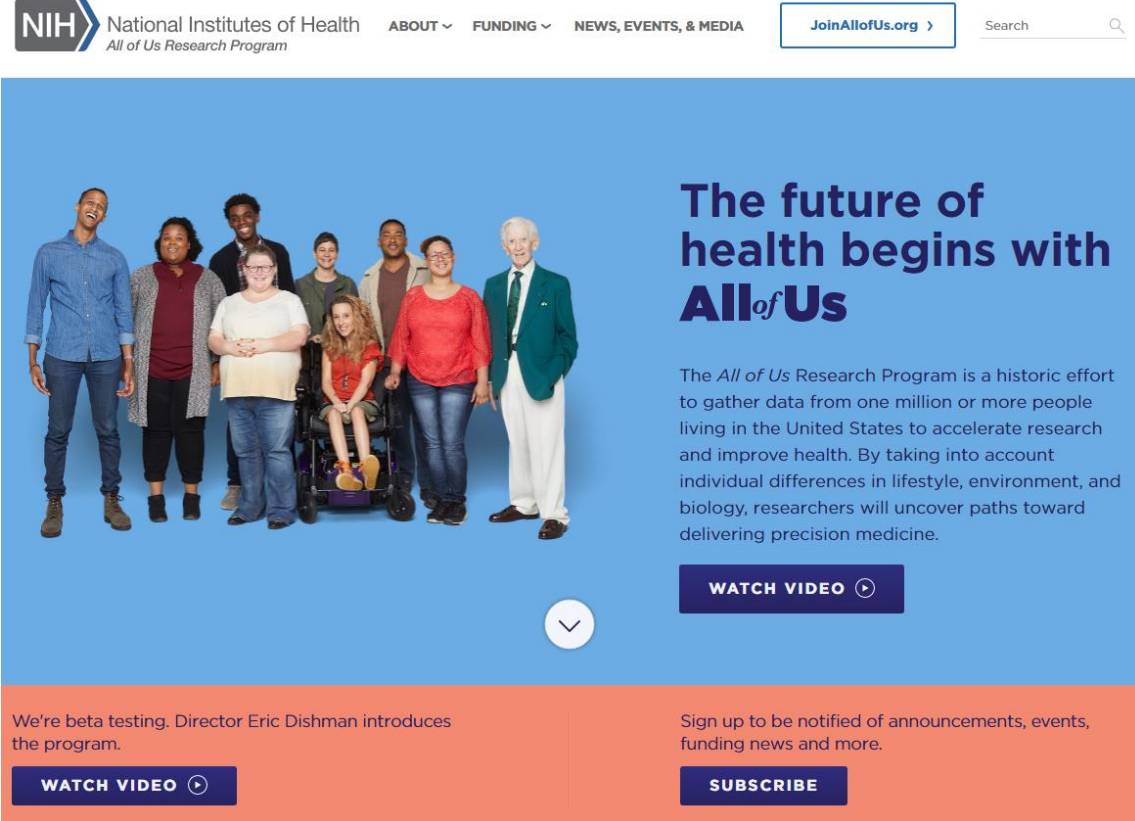
Precision medicine is an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.

Instead of what treatment is right for this disease it is what treatment is right for the patient.

[Precision Medicine Initiative announcement](#)

All of Us Research Program

The mission of the *All of Us* Research Program is to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us.



The screenshot shows the top of the All of Us Research Program website. At the top left is the NIH logo and the text 'National Institutes of Health' and 'All of Us Research Program'. To the right are navigation links: 'ABOUT', 'FUNDING', and 'NEWS, EVENTS, & MEDIA'. Further right is a 'JoinAllOfUs.org' button and a search bar. Below the navigation is a large blue banner featuring a diverse group of people of various ages and ethnicities. To the right of the group, the text reads 'The future of health begins with All of Us'. Below this text is a paragraph describing the program's mission: 'The All of Us Research Program is a historic effort to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, environment, and biology, researchers will uncover paths toward delivering precision medicine.' Below the paragraph is a 'WATCH VIDEO' button. At the bottom of the banner is a small white circle with a downward arrow. Below the banner is a red section with two columns of text. The left column says 'We're beta testing. Director Eric Dishman introduces the program.' and has a 'WATCH VIDEO' button. The right column says 'Sign up to be notified of announcements, events, funding news and more.' and has a 'SUBSCRIBE' button.

NIH National Institutes of Health
All of Us Research Program

ABOUT FUNDING NEWS, EVENTS, & MEDIA

JoinAllOfUs.org Search

The future of health begins with All of Us

The All of Us Research Program is a historic effort to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, environment, and biology, researchers will uncover paths toward delivering precision medicine.

WATCH VIDEO

We're beta testing. Director Eric Dishman introduces the program.

WATCH VIDEO

Sign up to be notified of announcements, events, funding news and more.

SUBSCRIBE

[All of Us Research Program](#)

All of Us Research Program- video



[What is All of Us? video](#)

All of Us – more information



The future of health begins with **All of Us**

The *All of Us* Research Program is a historic effort to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, environment, and biology, researchers will uncover paths toward delivering precision medicine.

WATCH VIDEO ▶



We're beta testing. Director Eric Dishman introduces the program.

WATCH VIDEO ▶

Sign up to be notified of announcements, events, funding news and more.

SUBSCRIBE

[All of Us Research Program](#)

Library role

“Preparing the public to make educated personal and family health decisions in a time of rapidly evolving genetic and genomic knowledge will require new partnerships between the education system, health care systems, the government, community advocacy organizations, consumers and the media.”

Show What You Know!

1. The CDC's top 10 causes of death all have a genetic component.
True or False?
2. The American College of Medical Genetics and Genomics (ACMG) recommends everyone should use a direct to consumer genetic test.
True or False?
3. What is the name of the research program that is looking to collect data on 1 million volunteers in order to provide more precise health care through prevention and treatment?
4. GINA (Genetic Information Nondiscrimination Act) protects you from life insurance discrimination.
True or False?
5. What resource would you recommend to patrons who wanted to learn more about genetic testing?

Thank You!

Carolyn Martin, MLS, AHIP
NNLM PNR
martinc4@uw.edu

Bobbi Newman, MLIS, MA
NNLM GMR
bobbi-newman@uiowa.edu

